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Eliciting gastric cancer survivors' preferences for follow-up services: a discrete choice experiment protocol

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ABSTRACT

Introduction Follow-up care is important for gastric cancer survivors, but follow-up strategies for gastric cancer survivors remain inconsistent, and compliance of gastric cancer survivors with follow-up care is very low. Understanding the needs and preferences of gastric cancer survivors is conducive to developing appropriate and acceptable follow-up strategies, thereby improving patient compliance. Discrete choice experiments can quantify individual needs and preferences. However, to date, there is no discrete choice experiment on the preferences of gastric cancer survivors, and no studies have examined how gastric cancer survivors make choices based on different characteristics of follow-up. This paper outlines an ongoing discrete choice experiment that aims to (1) explore follow-up service-related characteristics that may affect gastric cancer survivors' choices about their follow-up, (2) elicit how gastric cancer survivors consider the trade-offs among different follow-up service options using discrete choice experiment, (3) determine whether gastric cancer survivors' needs and preferences for follow-up vary due to the economy, politics, technology and culture in different regions.

Methods and analysis Six attributes were developed through a literature review, semistructured interviews and experts and focus group discussions. A fractional factorial design was used to evaluate the interaction between attributes. A multiple logit model will be used to understand the trade-off between the follow-up characteristics of gastric cancer survivors. A mixed logit model will be used to explore the willingness to pay and uptake rate of gastric cancer survivors for follow-up attributes and further explore the preferences of different groups.

Ethics and dissemination This study was approved by the ethics committee of the School of Nursing, Jilin University. The results of this study will be shared through online blogs, policy briefs, seminars and peer-reviewed journal articles and will be used to modify the current strategy of gastric cancer survivors' follow-up services according to economic development and regional culture.

INTRODUCTION

Gastric cancer constitutes a worldwide public health burden and the fourth most common type of malignant tumour.[1] Persons with tumours, have completed the main tumour

Strengths and limitations of this study

► To the best of our knowledge, this is the first study to explore the follow-up preferences of gastric cancer survivors using a discrete choice experiment.
► A comprehensive literature review and qualitative research to determine the attributes and levels will ensure the authenticity and value of the research results.
► Discrete choice experiment explores stated preferences. Since there is no database on the follow-up of gastric cancer survivors in China, and it will take an extended period of time to establish one in the future, it is impossible to obtain the revealed preferences of gastric cancer survivors; thus, comparison of the consistency between the stated preferences and revealed preferences in this study is not feasible.
► Considering hard-type factors such as time and economy, six attributes are included in the study, and four attributes are excluded, which may have a certain impact on the results.

treatment, do not have active tumours, have no cure but are in long-term remission are called cancer survivors.[2 3] With the development of chemotherapy, surgery and radiotherapy, the survival rate of gastric cancer has increased significantly.[4] Data from the Surveillance, Epidemiology, and End Results Program indicated that the survival rate for gastric cancer was increased from 4% in 1973 to 30% in 2010 https://seercancergov/. In Asian countries, the survival rate of gastric cancer is higher, up to 45.4%.[5] However, the overall quality of life of gastric cancer survivors is not high.[6] They are worried about cancer recurrence and suffer from gastrointestinal discomfort, anaemia and osteoporosis complications.[7 8] Studies have shown that regular follow-up can detect tumour recurrence and metastasis earlier.[9 10] In addition, the postoperative follow-up of patients with gastric cancer has other advantages such as reducing postoperative complications,[11 12] monitoring for recurrence and metastasis of

gastric cancer[11] and determining the patients' psychosocial problems and providing appropriate support and help.[11 13]

The needs and preferences of gastric cancer survivors must be considered in the formulation of follow-up strategies, which affect the compliance of gastric cancer survivors to follow-up. Patients' needs and preferences for follow-up may be affected by the characteristics of the disease, economy, politics, technology and culture. Although some factors related to follow-up preferences have been analysed to date, there has been no research that has compared and validated the importance of these factors in patients with gastric cancer. Thus, understanding gastric cancer survivors' needs and preferences for follow-up services will be conducive to developing a follow-up strategy that will ensure the compliance with follow-up of gastric cancer survivors. To our knowledge, this study will be the first to measure and quantify the preferences of gastric cancer survivors towards follow-up services using a discrete choice experiment (DCE).

This DCE is being conducted across different regions of economic development in China. The incidence of gastric cancer constitutes a heavy burden on China, which is the largest developing country. According to cancer statistics, the estimated number of new cases of gastric cancer in China is 679 000 every year, accounting for 42.6% of the global total.[14] Some studies have shown that cancer survivors have similar needs and preferences for follow-up to some extent due to the similarity of disease characteristics and treatment processes.[15–23] Therefore, understanding the follow-up service preferences of Chinese gastric cancer survivors has reference value and guidance significance for the development of global follow-up service strategies. In DCEs, follow-up service-related attributes and levels are the key to assessing individual preferences for gastric cancer survivors. Therefore, this paper describes the methodological details of our ongoing DCE study.

The aims of this study are to explore the factors that influence gastric cancer survivors' follow-up compliance. The objectives of the study are as follows:

1. To explore follow-up service-related characteristics that may affect gastric cancer survivors' choices about their follow-up.
2. To elicit how gastric cancer survivors consider the trade-offs among different follow-up service options.
3. To ascertain whether gastric cancer survivors' needs and preferences for follow-up vary due to the economy, politics, technology and culture in different regions.

METHODS AND ANALYSIS
Study setting
This study is mainly conducted in the four provinces of Guangdong, Jilin, Sichuan and Gansu, which are located in southern, northeastern, southwestern and northwestern China, respectively. In addition, the four provinces have different levels of economic development,

with Guangdong representing economically developed regions, Jilin Province and Sichuan Province representing moderately developed economic regions, and Gansu Province representing economically backward regions. These provinces have a certain representation in terms of geographical and economic development, which is convenient for exploring whether gastric cancer survivors in different regions have different preferences.

Design
Our study used a DCE to explore the preferences of gastric cancer survivors for follow-up services, which includes four main stages: identifying and defining attributes and levels, generating choice sets and designing questionnaire, collecting the survey data and the analysing and explaining the results.[24 25] The development process of the DCE is shown in figure 1.

Identifying and defining attributes and levels
Literature review, group discussions and one-on-one semistructured interviews
A comprehensive review of the literature is important to help identify conceptual attributes and provide a basis for qualitative research. For this review, we searched the literatures related to follow-up of gastric cancer survivors on EMBASE, PubMed, China National Knowledge Infrastructure (CNKI) and WANFANG DATA. Our retrieval strategy was as follows: ("Gast*" OR "Gastric tumour" [MESH]) AND ("Surv*" OR "Survivors"[Mesh]) AND ("follow*" OR "surveillance" OR "monitoring") AND ("Patient Satisfaction"[Mesh] OR "Patient Preference"[Mesh]). At the same time, to obtain more comprehensive information, we reviewed the references of the retrieved documents. After screening the search results, we selected studies on complications, psychological condition, life status and other aspects of gastric cancer survivors and studies on the preferences and needs regarding the care provider, dietary guidance and access to information of other cancer survivors. In addition, considering the special situation of China, some specific institutional factors must be considered to explore other concepts, such as cost. Finally, we developed a list of potential attributes and levels (see online supplemental 1 for details) and explored them in more detail in the following focus-group discussions (FGDs) and one-on-one interviews.

FGDs and one-on-one interviews
The purpose of FDGs and one-on-one interviews is to further explore the conceptual attributes derived from the literature review and obtain new and contextual attributes from the perspective of gastric cancer survivors and experts. The topics of FDGs and one-on-one interviews mainly include the following: (1) the attitudes and views of gastric cancer survivors towards follow-up, (2) the conditions of gastric cancer survivors after discharge and available follow-up strategies, (3) the accessibility of medical services and (4) the availability of emotional or financial resources.
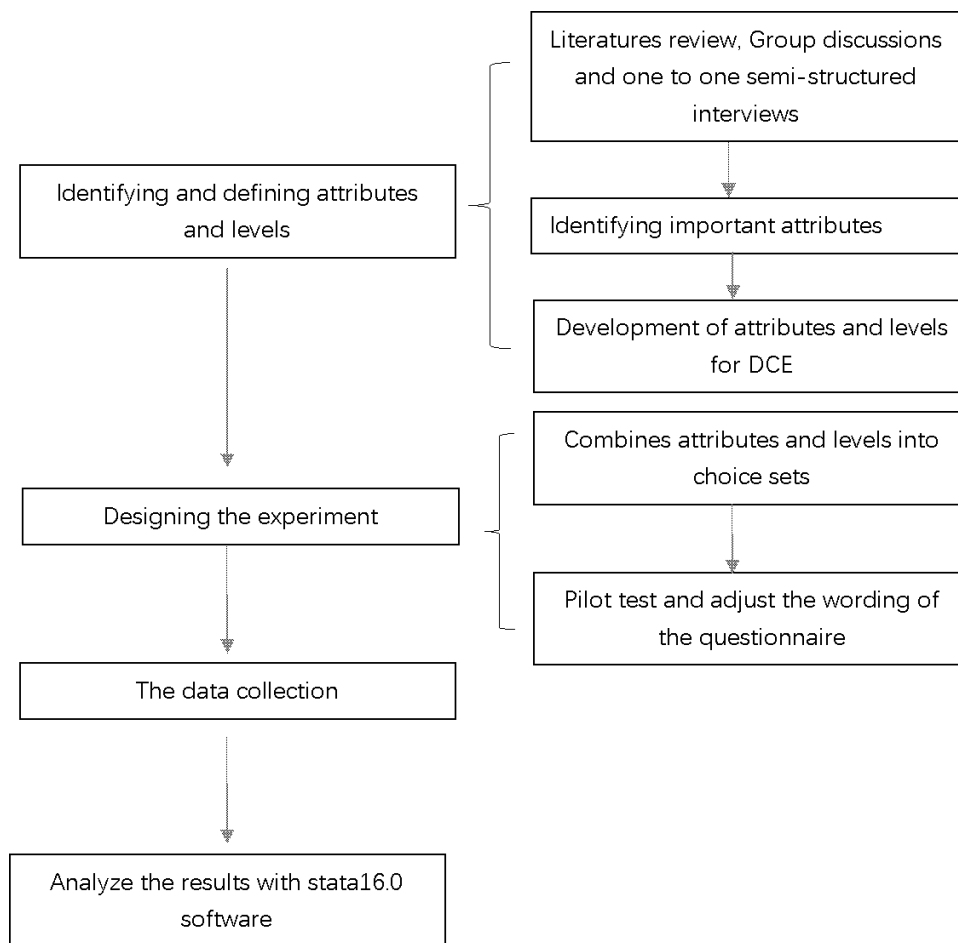
Figure 1 The development process of the DCE. DCE, discrete choice experiment.

To ensure enough heterogeneity, we performed targeted sampling based on province, age, tumour stage, level of education and primary caregiver among the population. FGDs and one-on-one interviews were conducted separately for gastric cancer survivors and experts (one doctor, one nurse and one health economist who have worked for more than 10 years) by two researchers. In addition, the first author recorded the views of the participants in the FGDs. During the one-on-one interview, the author C recorded all the interviews and then transcribed verbatim by professional personnel.

Each of the four provinces representing different levels of economic development has a focus discussion group, and each focus discussion group consists of five gastric cancer survivors. The final four focus groups allowed us to determine the full range of relevant features that affect the participation of gastric cancer survivors in follow-up. Fifteen gastric cancer survivors and three experts received one-on-one interviews.

Before recruiting patients as interviewees, we confirmed that the patients knew their disease, and then participants were recruited by the people who were responsible for cancer follow-up of the participants. No direct contact between researchers and potential participants was allowed without the patients' permission. In addition, before each interview, the participants were informed

of the purposes of the study and the interview, and all consents for the interview were anonymous and only used for scientific research. Participants were allowed to terminate the interview at any time during its course.

Qualitative analysis of FGDs and one-on-one interviews

Two authors (authors HJH and ZXY) and another (author WGY) who were not involved in the facilitation of the FGDs and the literature review analysed the notes and qualitative data from the records of the in-depth interviews using the qualitative method of thematic analysis.[26] To define and compare all major and minor themes, the three researchers independently read and analysed the transcripts. After being summarised in the text and tables, these themes were interpreted and discussed with coresearchers to obtain the coresearchers' opinions and form a broader attribute list.

New attributes were revealed in FGDs or interviews. Our research shows that the thoroughness of health-related information, especially the recognition of post-operative complications and recurrence symptoms, was of paramount importance in influencing patients' decisions about seeking or accepting follow-up. It is important that how many years of follow-up is required. At the same time, gastric cancer survivors expect to receive additional

services when needed, such as treatment of complications, psychosocial support and health behaviour advice.

Participants emphasised that the follow-up method on their participation in follow-up was important for determining communication effectiveness and convenience. Moreover, continuity of follow-up is important for participants and they hope that the same person will always provide follow-up. In addition, the participants preferred to consult with gastrointestinal specialists (mainly referring to doctors) and specialist nurses. It is particularly noteworthy that many of them preferred specialist nurses during the follow-up. This is similar to two previous studies of follow-up preferences in breast cancer survivors,[27 28] in which participants showed a preference for specialist nurses. This shows that specialist nurses play an important role in follow-up services.

Cost seems to be a potential barrier affecting gastric cancer survivors' participation in follow-up. At present, follow-up costs for gastric cancer survivors are not covered by China's Medical Insurance System. Therefore, patients have to pay out-of-pocket for follow-up services. In particular, distance travelled seemed to be a factor for patients from the countryside where primary care providers and professional services are lacking. Therefore, the patients have to pay additional costs associated with expenses related to accommodation, fuel, parking and time away from work when they have to travel to the city for follow-up. This may also be one of the reasons why gastric cancer survivors focus on the location of follow-up and prefer institutions close to home. In addition, experts believe that the consultation form of follow-up is important for gastric cancer survivors. Experts pointed out that the patient's education level was a potential factor affecting gastric cancer survivors' participation in follow-up. Patients with a lower level of education were less likely to participate in follow-up.

Development of attributes and levels for DCE

After the literature review, FGDs and one-on-one interviews, 10 key features related to gastric cancer follow-up were identified. These attributes are as follows: 'thoroughness', 'location', 'frequency', 'provider', 'total years of follow-up services', 'cost', 'method', 'consultation', 'continuity' and 'supplementary services'. Although the number of attributes was not restricted in the DCEs, fewer than 10 attributes were suggested to reduce the cognitive burden on the respondents.[29] Referring to a DCE to assess adherence-related motivation,[30] the importance of every attribute was divided into the following three levels: most, somewhat and least. Participants were asked to vote for each attribute with most, somewhat and least. Then, according to the number of 'most' votes, the attributes were sorted, and the priority of the attributes was determined.

Four to eight attributes were involved in most of the DCE studies.[31] In our study, according to the ranking results, six attributes, 'thoroughness', 'provider', 'cost', 'method', 'continuity' and 'supplementary services',

were finally included in this study. These attributes formed the basis of the final DCE design of this study. Notably, 'thoroughness' was the focus issue of numerous gastric cancer survivors and was, thus, ranked first. In the context of enhanced recovery after surgery, the hospital stay of gastric cancer patients was significantly shortened. The gastric cancer survivors hoped to obtain more detailed and clear answers during follow-up services.

Levels were assigned to each attribute according to the potential levels indicated in the literature, the participant's description about attributes and the expert's recommendations, which are applicable to the current health system. The levels of some attributes, 'cost' in particular, were difficult to define because of individual variance, such as the choice of transportation modes and accommodations. After consulting the experts, only the costs for follow-up itself were considered. The final attributes and their levels are detailed in table 1.

Generating choice sets

A full fractional design that incorporates all possible combinations is considered the most ideal method because all interaction effects can be investigated. In our study, four attributes had three levels, respectively, and the other two attributes had two levels, respectively. According to the full factorial design, the combination of attributes and levels resulted in 324 choice pairs ($3^4 \times 2^2 = 324$). However, it was very difficult for gastric cancer survivors to consider a large number of choice sets, which would cause a high cognitive burden and consume too much time and economic resources.

Thus, the fractional factorial design developed by Burgess and Street in Ngene was used to limit the number of choice sets.[32] Finally, 36 choice sets were generated using Ngene. The DCE design was orthogonal for main effects, and the estimated efficiency of the main effects was 100%. Furthermore, each attribute level appeared only once in a choice set and occurred the same number of times in all profiles, which created balance with minimal overlap. In summary, the DCE design met the statistical efficiency requirements.

In order to alleviate the cognitive burden on the respondents, 36 choice sets were randomly divided into four blocks of nine choice tasks each. To confirm whether the participants' choices represented their true thoughts, the second choice set of each block was repeated as the tenth choice set to test the consistency of the participants' choices and research quality (the choice set was not included in the data analysis). Ultimately, each block contained 10 choice sets. In addition to two profiles, an exit option (unwilling to participate in follow-up) was set in each choice set to reflect the follow-up compliance of gastric cancer survivors. Participants were asked to choose an option that they preferred for each choice task. An example of a choice set is shown in figure 2.

Table 1 List of attribute and levels

Attribute	Level	Description
Cost (¥)	100	Each follow-up cost is ¥100.
	300	Each follow-up cost is ¥300.
	500	Each follow-up cost is ¥500.
Thoroughness	Very thorough	Service providers answer your questions very clearly and completely. Not only to solve the problems associated with the disease but also to answer the questions related to social psychology, quality of life and so on.
	General thorough	Service providers clearly explain the problems associated with disease, but pay less attention to the questions related to social psychology, quality of life and so on.
Provider	Gastrointestinal surgeon	They have received specialised training in the diagnosis and treatment of gastrointestinal surgery.
	General practitioner	They provides person centred, continuing, comprehensive and coordinated whole person healthcare to individuals and families in their communities. This is patients own local doctor whom patients normally see when they get sick (eg, coughs and colds, blood pressure, diabetes, infections, etc).
	Specialised nurse	A registered nurse who has completed extra study in the specialty of gastrointestinal nursing or its equivalent.
Way	Face to face	You will be face-to-face with the service provider.
	Telephone or We-chat	You will communicate with the service provider by telephone or We-chat.
	Alternate between face-to-face and telephone/We-chat	If you communicate with the service provider by telephone/We-chat this time, next time is face-to-face communication, etc.
Continuity	Yes	Follow-up services were performed by the same person.
	No	Follow-up services may be performed by different people.
Supplementary services	Treatment of complications	The main supplementary service is the treatment of complications.
	Psychosocial support	The main supplementary service is psychosocial support.
	Health behaviour suggestions	Staff members provide you with advice, such as diet and exercise, to both develop and maintain good health and reduce the risk of gastric cancer returning.

Questionnaire design and pilot testing

The questionnaire consists of three parts, followed by a unified introduction, general information questionnaire and DCE choice tasks. Uniform instructions introduced the purpose of the study and the requirements for completing the questionnaire. Sociodemographic characteristics such as gender, age, income, tumour stage and education level are included in general information questionnaire to explore how they might influence preferences. It is noteworthy that before choice tasks, each attribute and its levels are described in detail to help participants understand. The purpose of the pilot test was to assess participants' cognitive burden, level of understanding and face validity of the questionnaire. The pilot testing consists of two parts: participants filled out the DCE questionnaires and underwent the personal cognitive interview. The number of completed items and the completion time were recorded to assess the burden on participants. Personal cognitive interviews were used to examine participants' understanding of the levels and the face validity of the questionnaire.[33] At present, there is no clear guidance on how to determine the sample size of the pilot test in the DCE. To maximise the heterogeneity of the

samples in this study, we referred to the pilot test samples of other DCE designs (N=6–24).[34–36] Eventually, 17 gastric cancer survivors from different provinces were included in the pilot test. First, all participants were required to 'think aloud' in the process of completing each choice set.[37] In the 'think aloud' exercise, participants were encouraged to consider all attributes and make trade-offs among them and then select the profile with the factors likely to promote participation in follow-up. A retrospective probing following DCE completion was completed by a face-to-face or telephone interview, which was used to refine the wording, comprehension and options of the DCE.[38] All 17 gastric cancer survivors completed the questionnaire with an average completion time of 5.3 min. No suggestion for deleting or adding items resulted from the qualitative data from cognitive interviews. Moreover, most of the 17 participants describing length referred to it as 'not too long' or 'acceptable'. Therefore, the burden on participants was acceptable. Nevertheless, a few of the 17 participants felt that the questionnaire was somewhat difficult and confusing to understand, which suggested that the questionnaire might be burdensome and cognitively demanding to our group of gastric cancer survivors

You will be asked to answer questions about the hypothetical follow-up programme for gastric cancer. We provide the following selection cards, each of which contains two schemes. Their characteristics will be different in the following six aspects:

Thoroughness: how clear and complete is the follow-up services provider's explanation of your situation.
Provider: who provides you with post-discharge follow-up information.
Cost(￥): the cost of each follow-up service(including some examination fees and registration fees, but not including additional costs such as travel, accommodation and fuel.)
Method: appointment method of follow-up services.
Continuity: each follow-up service is provided by the same staff member.
Supplementary service: in addition to the days of regular follow-up, the help and guidance provided by the staff.

An example of choice set.

Attributes	ProgrammeA	Programme B
Thoroughness	very thorough	general thorough
Provider	general practitioner	specialized nurse
Cost(￥)	500	100
Method	Alternate between face-to-face & telephone/We-chat	Telephone or We-chat
Continuity	No	Yes
Supplementary service	Treatment of complications	Secondary prevention of cancer.

Which Programme do you prefer：

☐Programme A   ☐Programme B   ☐Unwilling to receive follow-up services

Figure 2 An example of choice set.

to some extent. In this regard, we adjusted the questionnaire according to the feedback of the participants, which included (1) adjusting the wording in the questionnaire and (2) adding a choice task example to demonstrate how to fill in the questionnaire. In future studies, we will recruit respondents and then use adjusted questionnaires to collect information on the needs and preferences of gastric cancer survivors.

Sampling and recruitment

The target population of this study is gastric cancer survivors. Criteria are as follows: (1) tumour stages I–III and completion of the main treatment, (2) clear expression and (3) age ≥18 years. The exclusion criteria are as follows: (1) patients with other malignancies. (2) patients with other complicated serious cardiovascular diseases, (3) patients who are physically weak and unable to accept the interview and (4) patients with hearing impairment.

Sample size calculation for DCEs in healthcare depends on the desired precision of the results, the complexity of the choice tasks, the question format, the availability of the respondents, the heterogeneity of the target population and the need for subgroup analysis.[39] To date, researchers have commonly applied a rule of thumb to estimate sample sizes based on the number of attribute levels.[40] In our study, the sample size calculation is based on the rule of thumb proposed by Johnson and Orme.[41 42] According to Johnson and Orme, the calculation formula of the minimum sample size N is shown in the following equation:

$$n > 500 \, c/(t \times 4)$$

In this equation, t is the number of choice sets faced by each individual (excluding the selection set repeatedly included), a is the number of alternatives in each choice set (excluding exit items) and c is the number of analysis cells (when considering the main effect, c is equal to the maximum level number of any attribute). The minimum sample size needed in each version of the questionnaire is 84 (t=9, a=2, C=3). We plan to mark the four versions of the questionnaire with 1, 2, 3, 4 and use them in Guangdong, Jilin, Sichuan and Gansu, respectively. Considering that 30% of the recovered questionnaires may be invalid, we will recruit 110 gastric cancer survivors in each province (the total sample size is 440 participants) to ensure that sufficient data to be included in the analysis and obtain wide representativeness. We will obtain the e-mail address and WeChat of gastric cancer survivors in the cancer registries of 12 general hospitals in the four provinces. All 12 general hospitals are capable of concurrently treating more than 1000 inpatients with various diseases and undertaking major local cancer follow-up services,

which are representative in their respective provinces. Individuals who have completed the main tumour treatment and have no active tumours are called cancer survivors.[2] [3] Therefore, we will investigate patients with gastric cancer within 1 month after they complete surgery and/or chemotherapy and are confirmed that they had no active tumours through medical examinations, in order to reduce the bias caused by the difference in survival time. Questionnaires will be distributed to participants, with the preferred distribution method being face-to-face. If participants requested an electronic questionnaire, they will be provided the questionnaire via WeChat or e-mail. Each patient will only receive questionnaire once. All questionnaires will be administered in Mandarin, which is a common language throughout China and widely used in daily speaking, writing, teaching and official documents.

Affected by COVID-19 pandemic, participant recruitment for this study started in May 2019 and will be completed in December 2021.

Patient and public involvement

Patients and/or the public were not involved in the design, conduct, reporting or dissemination plans of this research.

Analysis plan

The trade-offs between the features of follow-up services included in the choice tasks will be explored using the multinomial logit (MNL) model. The analysis of the preferences of gastric cancer survivors for follow-up will help us explore which patients and factors (and levels) influence gastric cancer survivors' choices for follow-up services. According to their options, the importance of these factors (and levels) and their interactions with patient-related characteristics will be established (such as gender, age, income, tumour stage and level of education).

The MNL model has the characteristics of a low error rate, low technology maturity and low sample requirements.[43] Using the MNL model as a framework in the early stage will help the overall optimisation of the model, including finding more explanatory variables and making the factor level more reasonable.[44] Moreover, since the predictable differences in preferences will be the focus of our research, the MNL method will be used for preliminary analysis. However, the MNL model ignores individual heterogeneity and cannot handle random preference differences, and the mixed logit model makes up for these deficiencies, which allows the coefficients of explanatory variables to be random.[45] In the mixed logit model, a regression with each of the parameters interacting with each of the sociodemographic characteristics in turn will be run to explore differences in preferences between different groups. Furthermore, the cost attribute will be modelled as a continuous variable to estimate the respondents' willing to pay (WTP), which is the amount of money respondents are WTP to obtain the improvement or worsening of an attribute. The nlcom command will be used to simulate the uptake rate; that is, when the levels of one or more attributes change compared with the baseline follow-up programme, then the probability of a participant receiving a follow-up programme will be changed.

Ethics and dissemination

This study was approved by the Ethics Committee of the Jilin University. Participant recruitment for this study started in May 2019 and will be completed in December 2021. Similar to FGDs and one-on-one interviews, before the questionnaire survey, the information of the study, such as the nature, objectives and possible risks, will be explained to the participants, and written informed consent will be obtained. All information-related participants will be anonymous, and all data will be used only for scientific research. Furthermore, participants have the right to withdraw from this study at any time.

The DCE analysis will provide comprehensive coverage of gastric cancer survivors' preferences towards features of their follow-up and explore preference heterogeneity by economic development and regional culture. Specifically, the findings of our study could be used to modify the current strategy of gastric cancer survivors' follow-up services according to economic development and regional culture by the following: (1) emphasising priority areas of intervention based on the preferences of gastric cancer survivors; for example, if the participant shows a strong preference for the continuity of follow-up at the hospital, a special post can be set up to ensure that each gastric cancer survivor's provider is always the same person and (2) disseminating knowledge about the relative importance of the gastric cancer survivors' choice and promoting awareness of potential differences among gastric cancer survivors in regions with different economic development levels. The results of this study will be shared through online blogs, policy briefs, seminars and peer-reviewed journal articles.

of the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

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